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Assessing Individual Support Needs to Enhance Personal Outcomes

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Abstract

Education and human service organizations providing services to people with intellectual and closely related developmental disabilities are increasingly being impacted by the supports paradigm, the quality of life concept, and the evaluation of personal outcomes. In this article the authors discuss the relationship among these three areas, including examples that illustrate how assessed support needs data can be aligned with quality of life-related core domains so as to establish individualized support systems that enhance personal outcomes. The article concludes with a discussion of the implications for educators and habilitation professionals of integrating the supports paradigm, the quality of life concept, and the evaluation of personal outcomes.

There are two international trends in the field of intellectual and closely related developmental disabilities (ID/DD) that are significantly impacting the delivery of services and supports to persons with ID/DD. The first is to understand children and adults with ID/DD on the basis of their assessed support needs. The second trend is to use a quality of life conceptual and measurement framework to align an individual's support needs to the planning, delivery, and evaluation of individualized supports. Collectively, these two trends and their related processes focus on the enhancement of personal outcomes. The purpose of this article is to discuss these two trends and provide examples that illustrate how assessed support needs data can be aligned with core quality of life domains (QOL domains) so as to establish individualized support systems that enhance personal outcomes.

Contextually, these two trends reflect the changing conceptualization of disability from one that focuses on a person's defect/disability to an ecological focus on the person and his/her environment. Key components of this evolving disability paradigm are: (a) the social-ecological model of disability with its focus on reducing the mismatch between a person's skills and the demands of his/her environment and enhancing human functioning (Wehmeyer et al., 2008); (b) the supports paradigm with its focus on assessing the profile and intensity of one's support needs and achieving desired personal outcomes through the judicious application of individualized support systems (Thompson et al., 2009); and (c) the quality of life movement with its focus on person-centered planning, consumer empowerment and inclusion, and the achievement of personally meaningful life conditions and circumstances (Schalock et al., 2007).

Progress in any field is often contingent on the extent to which there is a clear understanding and a consensus on the meaning of important terms and concepts. To this end, throughout the article the following definitions of key terms and concepts are used:

- *Support Needs*: "a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning" (Thompson et al., 2009, p. 135).
- *Supports*: "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning" (Schalock et al. 2010, p. 109).
- *Personalized Support Systems*: the planned and integrated use of individualized support strategies and resources that encompass the multiple aspects of human performance in multiple settings (Thompson et al., 2009).
- *Quality of life*: "a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. These core domains are the same for all people, although they may vary individually in relative value and importance. Assessment of quality of life domains is based on culturally sensitive indicators" (Schalock et al., 2009, p. 10).
- *Personal outcomes*: "the benefits derived by program recipients that are the result, directly or indirectly, of program activities, services, or supports" (Schalock, Verdugo, Bonham, Fantova, & van Loon, 2008, p. 277).

Understanding People Based on Their Support Needs

Traditionally, people with ID/DD have had individualized education and/or habilitation plans that contained goals and behavioral objectives related to their level and profile of assessed adaptive behavior. Assessing a person's adaptive behavior was a critical step in identifying learning goals on which to focus interventions that promoted skill acquisition. In contrast, the supports paradigm requires assessing support needs to identify types and patterns of supports needed by a person to meaningfully participate in life activities. As a result of this emphasis, an

individualized plan may still contain learning goals and objectives that focus on increasing personal skill levels, but now the primary focus is on identifying and providing supports that enhance personal outcomes.

Key differences between the assessment of adaptive behavior skills and the assessment of support needs are summarized in Table 1. Although numerous adaptive behavior scales have been available for years (e.g., Bruininks et al., 1986; Sparrow et al., 2005), standardized instruments to assess the pattern and intensity of a person's support needs are less common. To address the need for a standardized approach to support needs assessment, *The Supports Intensity Scale* (SIS) was developed (Thompson et al., 2004). The *SIS* has been translated into 13 languages and is being used extensively internationally for multiple purposes at the individual, organization, and systems level (Buntinx et al., 2008). The interested reader can find recently published reliability and validity information on the *SIS* in Buntinx, Virginie et al. (2009), Claes, Van Hove, van Loon, Vandevelde, and Schalock (2009a), Lamoureux-Hebert and Morin (2009), Morin and Cobigo (2009), Thompson, Tassé, and McLaughlin (2008), and Wehmeyer et al. (2009). The *Children's SIS* is currently being field tested in the US and Canada on a child population ranging in age from 5 to 16 (Thompson, 2010).

The development of both the *SIS* (persons 16 years of age and older) and the *Children's SIS* (5-16) was based on a multiple step process that included a thorough review of the supports literature, focus group interviews, Delphi procedures to assign support areas to major life domains, and extensive field testing, item analysis, and standardization (Thompson et al., 2004; Thompson, 2010). These efforts resulted in an instrument that assesses the pattern and intensity of support needs based on the *frequency* of needed support, the *daily support time*, and the *type* (i.e., nature) of support. A separate section of each instrument assesses the amount of support needed to improve or maintain health due to exceptional medical support needs and to prevent or

minimize undesirable consequences stemming from behavioral problems or disorders. A comparison of support need areas evaluated on the *SIS* and *Children's SIS* is presented in Table 2.

Using a Quality of Life (QOL) Conceptual and Measurement Framework To Align Support Needs to Personal Outcome Categories

The framework shown in Table 3 reflects the considerable international research on operationalizing the quality of life (QOL) concept through the identification of QOL factors, core QOL domains, and QOL-related indicators (Jenaro et al., 2005; Schalock et al., 2005; Wang, Schalock, Verdugo, and Jenaro, 2010). The three factors listed (independence, social participation, and well-being) represent higher order constructs and integrate the eight core QOL domains. These eight domains, which have been shown to have etic (i.e. universal or culture-free) properties, represent the range over which the quality of life concept extends and thus define the multidimensionality of a life of quality. QOL indicators, which have emic (i.e. culture-bound) properties, are domain-specific perceptions, behaviors, and conditions that give an indication of a person's well-being. The exemplary indicators listed in Table 3 are the most common indicators for each of the eight core domains based on an international review of quality of life literature in the areas of education and special education, intellectual disability, mental and behavioral health, and aging (Schalock & Verdugo, 2002). These indicators are used to operationalize each QOL domain and are the basis for assessing QOL-related personal outcomes.

Assessing personal outcomes involves the subjective and objective measurement of culturally relevant indicators associated with each of the eight core QOL domains listed in Table 3. This approach was used in developing the *Personal Outcomes Scale* (*POS*; van Loon, Van Hove, Schlock, and Claes, 2008). Indicators within each domain were developed and validated in the Flemish speaking part of Belgium and the Netherlands using focus group interviews and

expert panel reviews. The focus groups included persons with intellectual disability as well as parents and professional staff, and the expert panels were composed of individuals in leadership positions in the field of ID/DD (e.g., academics, government workers, and human service program administrators, and experienced practitioners). Each item on the POS is evaluated on a 3-point Likert-type Scale under two conditions: subjective (self report) and objective (direct observation).

Aligning Support Needs to Quality of Life Domains (QOL Domains)

In this section of the article we describe how the Arduin program in the Netherlands uses support needs data and personal outcome measures based on the quality of life framework presented in Table 3 to develop, implement, and evaluate person-centered individualized support plans. A detailed description of the Arduin program can be found in van Loon and Van Hove (2001). The person-centered approach to individualized planning used in Arduin is a systematic process that is based on collecting and considering a range of input, throughput (i.e. programmatic activities) and outcome variables.

Input

The input is what a person brings to the planning process. Specifically, information is collected on the person's *current* goals and perspectives related to a life of quality and the pattern and intensity of the person's support needs.

*Goals and perspectives***.** Goals and perspective change throughout one's life, and it is important that identifying goals and perspectives is not an episodic, "one session" event. However, to start this important dialogue, a structured interview is held with the person and his or her parents. The purpose of the interview is to gather information about the person's desired life experiences and goals. The interview is structured according to life activity areas of the *SIS.* In this interview, the person is asked questions regarding each section of *SIS* (see Table 2) to

determine current status as well as preferred or ideal status. A written record of information uncovered during the structured interview is maintained in an electronic format in a password protected, secure database. Members of an individual's core planning team (including the person with the disability and his/her parents) can access and update this information at any time through the Internet. This not only provides transparency to the planning process, but information is easily updated as dialogues regarding goals and perspectives change.

Support needs. The *SIS* (Thompson et al., 2004) is used to assess an individual's support needs. As with the structured interview that is focused on understanding personal goals and aspirations, the *SIS* is completed by interviewing the person with the disability and his/her social network (mostly parents or other family members). Also, Arduin has developed an electronic version for the Dutch translation of the *SIS* (Buntinx, 2006) that enables *SIS* data, just like information on goals and perspectives discussed previously, to be stored in a secure database that planning team members can access through the Internet.

Throughput

Once information from both sources (i.e., the structured interview on the person's desired life experiences and goals and the *SIS*) is gathered, a report is created that provides an overview of the goals/wishes of a person and the supports needed to achieve these goals. Arduin has also developed a computer program that generates a format to write an ISP based on this information. The first step in this process is to align the life activity areas assessed on the SIS with the core QOL domains summarized in Table 3. This alignment is shown in Table 4.

The second step is to relate the specific QOL domains and indicators to *SIS* life activity areas as well as the person's goals and perspectives. This step in shown in the first three columns in Table 5. The third step is to relate these three components to specific elements of the support plan. This relationship is shown in the final column of Table 5. In total, Table 5 presents two sections

from an actual Individual Support Plan that illustrate how specific supports are aligned with both the individual's assessed support needs and the respective QOL domains (Emotional Well-Being and Material Well-Being).

Outcome

Assessed personal outcomes are used to monitor and evaluate the impact of the support strategies used. As discussed earlier, these personal outcomes are referenced to the core QOL domains and are assessed (in the case of Arduin consumers) on the basis of the *Personal Outcomes Scale.* As discussed in more detail in van Loon et al. (2008), personal outcome data are used for multiple purposes including reporting, monitoring, evaluation, and organization-referenced quality improvement.

Discussion

The integration of the supports paradigm, the quality of life concept, and the evaluation of personal outcomes provide a logical framework for organizing and evaluating education and human service programs. To this end, the judicious application of individualized supports that are based on functional requirements according to environmental demands are more likely to enhance personal outcomes that those that focus only on an individual's deficits.

Throughout this article we have highlighted a systematic approach to an individualized support planning process developed by Arduin in The Netherlands. Arduin's planning process is unique among human service provider organizations since it is based on a logical framework of input (goals and perspectives; measured support needs), throughput (individual supports plan elements based on QOL domains and *SIS* assessment areas) and output (measured personal outcomes). The rationale for this framework is based on the following three premises: (a) human functioning is multidimensional, (b) the provision of individualized supports should enhance human functioning, and (c) the concept of quality of life provides a framework for service

provision and outcomes evaluation. The integration of the quality of life framework into support planning strategies as described in this article can also be used to evaluate service effectiveness and thus provide important information for demonstrating evidence-based practices (Schalock, Bonham & Verdugo, 2008; Claes, Van Hove, van Loon, Vandevelde, and Schalock, 2009b).

Our experiences with Arduin's approach to developing individualized support plans have resulted in three important implications for others who may want to align assessed support needs with quality of life-related personal outcome domains. First, interviewers of a support needs scale have to be familiar with the distinction between the assessment of adaptive behaviour and the assessment of an individual's support needs, and they also must be properly trained (Thompson et al., 2008; Claes et al. 2009a). Second, assessing support needs is a process that is best completed when insights are gathered from a variety of people who know the person with the disability well. For example, findings from a study by Claes et al. (2009a) on respondent reliability using the SIS indicated that despite an acceptable degree of inter-respondent reliability, there was a tendency for staff members to rate the consumers' needs for support higher than that provided by the consumer(s). The divergent perspectives of consumers and staff members corroborate the importance of the consumers' active participation in the support assessment process. Third, support needs assessment data should be combined with other information gathered from the person-centred planning processes, as planning and delivering supports are meaningful only when the supports enhance outcomes consistent with an individual's goals and desires.

The approach suggested in this article also has important implications for how human service organizations and schools approach their work. First, the alignment of support needs with desired personal outcomes involves emancipatory elements that include conditions of self-advocacy and personal empowerment. As a result, consumers and professionals form a

partnership, and the role of the professional is redefined from that of a caregiver to one who facilitates opportunities to experience an enhanced quality of life (van Loon & Van Hove, 2001). In this context, studying quality of life principles should be part of any professional development program that is focused on ethics that professional staff should bring to their work with persons with ID/DD. Second, it is essential that professionals recognize that individuals with ID/DD must have opportunities to make choices. Appropriate information and sources of support can provide a context so that authentic options and alternatives are available. Choices are only meaningful to a person when alternatives have been considered in light of the person's support needs, wishes, activities, values, and desired personal outcomes (Gillman, Heyman, and Swain, 2005).

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Table 1

*Differences between the Assessment of Adaptive Behavior and Support Needs**

Construct Measured:

- Adaptive Behavior Scales: The adaptive skills that a person has learned, which is a measure of achievement or performance
- Support Needs Scales: The extraordinary support that a person needs in order to participate successfully in major life activities

Focus:

- Adaptive Behavior Scales: To determine the pattern of adaptive behaviors displayed by the person
- Support Needs Scales: To determine the pattern and intensity of support needed to enhance participation in home and community life

Uses:

- Adaptive Behavior Scales: To diagnosis intellectual disability and to identify relevant educational and rehabilitation goals
- Support Need Scales: To determine a person's support needs in different areas of life relative to others with intellectual disability; to develop individualized support plans

Item Stems:

- Adaptive Behavior Scales: Observable and measurable adaptive behaviors or skills needed to successfully function in society
- Support Need Scales: An array of life activities encompassing multiple behaviors and skills in which a person engages while participating in society

*Adapted from Thompson et al. (2004)

Table 2

Comparison of Support Needs Assessed on the SIS and Children's SIS

Support Need Focus	SIS subscales (# items)	Children's SIS subscales (# items)
Home Living	Home Living Activities (8)	Home Life Activities (9)
Community Participation	Community Living Activities (8)	Community & Neighborhood Activities (8)
Education	Life-long Learning Activities (9)	School Participation Activities (9); School Learning Activities (9)
Employment	Employment Activities (8)	
Health & Safety	Health & Safety Activities (8)	Health & Safety Activities (8)
Socialization	Social Activities (8)	Social Activities (9)
Advocacy	Protection & Advocacy Activities (8)	Advocacy Activities (9)
Managing Medical Conditions	Medical Supports (16)	Medical Supports (19)
Managing Challenging Behavior and Behavior Disorders	Behavioral Supports (13)	Behavioral Supports (14)

Table 3

Quality of Life Conceptual and Measurement Framework

QOL Factor	QOL Domain	Exemplary QOL Indicators
Independence	Personal Development	Education status, personal skills, adaptive behavior (ADLs, IADLs)*
	Self-Determination	Choices/decisions, autonomy, personal control, personal goals
Social Participation	Interpersonal Relations	Social networks, friendships, social activities, relationships
	Social Inclusion	Community integration/participation, community roles
	Rights	Human (respect, dignity, equality), Legal (legal access, due process)
Well-Being	Emotional Well-Being	Safety & security, positive experiences, contentment, self-concept, lack of stress
	Physical Well-Being	Health status, nutritional status, recreation/physical exertion
	Material Well-Being	Financial status, employment status, housing status, possessions

*ADLs = Activities of Daily Living: IADLs =Instrumental Activities of Daily Living

Table 4:

Aligning QOL Domains with the SIS Assessment Areas

QOL Domain	SIS Assessment Areas
Personal Development	Health & Safety, Protection & Advocacy, Exceptional Behavioral Support Needs
Self-Determination	Protection & Advocacy
Interpersonal Relations	Social Activities
Social Inclusion	Community Living Activities, Social Activities
Rights	Protection & Advocacy, Health & Safety
Emotional Well-Being	Health & Safety, Protection & Advocacy, Exceptional Medical and Behavioral Support Needs
Physical Well-Being	Health & Safety, Exceptional Medical Support Needs
Material Well-Being	Employment Activities

Table 5

Sections of an ISP Aligning QOL Domains, Support Needs, and Desired Personal Outcome

QOL Domain & Indicators	SIS Areas	Goals & Perspectives	Support Plans
I. Emotional Well-Being Contentment Self-concept Lack of stress	Health & Safety Protection & Advocacy Exceptional Behavioral Support Needs	Ard wants to interact with others, but finds interactions stressful. He rarely initiates interactions, and is not confident in social situations. Daily support is needed so that he can enjoy the company of others and not withdraw and become lonely. He also needs support when he becomes distressed in social situations.	Monitor Ard's social interactions, and provide suggestions on what needs to be done when he is struggling in social situation, before he becomes distressed. If he becomes distressed, tell him that it is not necessary to be stressed, and tell him explicitly what he needs to do next. Be aware that Ard becomes distressed when his personal space is violated, especially when he is touched. Others should be reminded to not touch him. On days Ard is exceptionally distressed, there is a possibility to offer him medication.

Table 5 (continued)

Sections of an ISP Aligning QOL Domains, Support Needs, and Desired Personal Outcome

QOL Domain & Indicators	SIS Areas	Goals & Perspectives	Support Plans
III. Material Well-Being Financial status Employment Housing	Employment	Ard gets much satisfaction from his job and wants to continue with his 4-day per week employment. His employer needs reminders to alternate Ard's job duties as much as possible as Ard does not likes to do the same thing all day. Ard wants to learn how to lock his room when he is not at home.	Use taxi service to transport Ard to and from work. When at work, job coach must provide support at all times to assure that work quality and quantity meet expectations for continued employment. When starting new job activity, it must demonstrated repeatedly to Ard. On Wednesdays Ard needs to be reminded to bring 5 Euro to buy a special snack after work. Continue to work with Ard to lock and unlock his room when he leaves house. He needs full physical assistance to do this.